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Measuring Gender Satisfaction among Women Aging with Paralytic Polio

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Abstract

In this study we tested the Gendered Outcome Scale as a measure of gender satisfaction among 295 women aging with the disabling affects of paralytic polio. Principal components analysis, reliability analyses, and content validity were analyzed on the scale. The scale had a Cronbach's alpha of .90. Younger women had more gender satisfaction ($r = -.173, p < .01$), and women that had more disability had greater gender satisfaction. ($r = -.127, p < .05$). The results support that the scale was valid and reliable for measuring gender satisfaction. Further work is needed to test the scale in diversified samples.

Keywords

gender; polio; aging; older women; scale development

Gender roles can be said to consist of the expectations of society and its members about a person's behaviors and actions given his or her sex; the ability to fulfill these specified roles is surely affected by age as well as disability. Unique aspects of the aging process influence a person's ability to meet such expectations (Perrig-Chiello & Hutchinson, 2010). Especially persons aging with disabilities may have difficulty fulfilling socially prescribed gender roles. People with disabilities enact their gender roles when they interrelate with others (West & Zimmerman, 1987); as they portray themselves as men and women, they are vulnerable to the judgments about gender that others make. The outcomes of such interactions have implications for the overall health and well being of persons aging with disabilities. To understand how gender interacts with age in the context of disability, researchers must specifically examine how health disparities based on gender affect the lives of those aging with chronic conditions. Our purpose for this study was to psychometrically test the newly developed Gendered Outcome Scale in a sample of women aging with the effects of paralytic polio, and to examine the relationship between age, functional limitations, and disability with gender satisfaction within this sample. We intend to test the scale further for use among women aging with other chronic and disabling conditions as well.

The Gendered Outcome Scale can be used to measure gender satisfaction among women aging with chronic conditions. Because we could find no scales that could be used to measure gender outcomes in such women, we developed the Gendered Outcome Scale through studying the experiences of gender expressed by women aging with paralytic polio, who participated in a qualitative study of aging with disability (Harrison, 2006; Harrison & Stuijbergen, 2005). Here we present data from the use of the scale with a sample of 295 different women with childhood onset disabilities related to paralytic polio. Our use of the scale should provide further insight into the intersection of gender satisfaction, disability, and age. In addition, the scale can be further tested in other countries and cultures in order to contribute to international knowledge of the intersection of gender satisfaction, disability and age among people aging with chronic and disabling conditions world wide.

Background

Researchers have reported connections between gender outcomes and both health and health behaviors in various populations; however, there is little information on how gender outcomes influence health in women aging with chronic and disabling conditions. For example, Jones, Peskin, and Livson (2011), who explored differences in femininity in 327 men and women across 50 years, found that 61.2% of the women showed a decline in femininity across the lifespan and that they demonstrated better psychological health than did women who showed an increase in femininity. Moreover, in a study of gender differences between young men and women with cystic fibrosis, girls were found to be highly concerned with meeting normative definitions of femininity (Willis, Miller, & Wyn, 2001). The young women were less active, ate less, and had higher mortality rates than the young men did. The women placed normative gender expectations above participating in practices that would promote their health. Similarly, Neumark-Sztainer, Story, Falkner, Beuhring, and Resnick (1998) found that girls who showed malabsorption of nutrients related to their disease processes nevertheless preferred to be very thin rather than to correct their health problems. In a study of 20 adolescents with asthma and 20 adolescents with diabetes, Williams (2000) reported that because of social expectations surrounding gender roles, the females with diabetes often adapted their diet and exercise regimen in ways that were not beneficial to their diabetic outcomes.

The cultural image of the ideal female physique is difficult for most women to attain. This may contribute to eating disorders and low self-esteem in many women, but it can affect women with disabilities still more. Adolescent girls with disabilities have reported significantly higher use of laxatives, diet pills, and vomiting for control of body physique (Neumark-Sztainer et al., 1998). Among women with mastectomies due to breast cancer, normative evaluations of the female body have led many to choose reconstructive surgery, although few find it satisfying and it places them at risk for surgical complications (Kasper, 1995). The practices used to attain a feminine image may thus be in conflict with the practices needed to maintain health for those with disabilities. In using the Gendered Outcome Scale researchers are provided with the opportunity to gain further insight into gender outcomes and satisfaction in women aging with chronic and disabling conditions, and to determine whether these gender outcomes influence the health and health behaviors of these women.

There is limited research in which researchers use the perspectives of women with disabilities on gendered outcomes. For example, Valeras (2009) studied women's personal identification with their disabilities and how womanhood affected that identity process. She found that women with hidden disabilities developed an ability to transform their identities and needs depending on their situations. Malacrida (2009) conducted a qualitative study examining how 43 women with disabilities coped with the demands of motherhood. She reported that the women's stories showed the difficulties that women with disabilities often have in fulfilling both feminine roles and expected motherhood roles. Cultural expectations can hinder the integration of women with disabilities into society and have been used to explain the differential treatment that these women receive in performing gender roles such as that of a wife (Parker, 1993) or mother (Harrison & Stuifbergen, 2002; Thomas, 2001; Thorne, 1990). There is a growing consensus among disability experts that more research is needed to examine gender outcomes and gender satisfaction from the perspectives of women aging with disabilities.

It was not until Campbell, Sheets, and Strong (1999) reported a quantitative study of impairment-related outcomes based on the timing of disability in the life span that gender was considered to be an influence on the life course of persons with disabilities. Campbell et al. studied three groups of persons aging with disabilities—those with polio, stroke, and rheumatoid arthritis. The time of disability onset was significantly related to the degree of impairment. Women who developed postpolio syndrome (PPS), which is characterized by new onset weakness and fatigue, had significantly more depressive symptoms than did women without PPS. They also had higher depressive symptoms than did men with or without PPS. Women were also more likely to have had to stop their education as a result of their polio-related impairment than were men. Campbell et al. compared outcomes based on gender using a life course theory approach. Harrison, Stuifbergen, Walker, Scott, and Choban (2011) conducted a qualitative study on the influence of gender in those aging with the effects of child onset of polio. They found that the women's perception of gender outcomes was influenced by their impairments; the women's behaviors could be feminine or masculine, depending on the demands of society. The women felt that they had to be strong and independent to assert their needs surrounding their impairments, which was not always the gendered behavior expected from women. In both of these aforementioned studies the researchers recommended that further work be done to obtain an understanding of how gender affects the health-related behaviors and outcomes associated with aging in persons with early onset disabling conditions; polio was their exemplar.

Typically, paralytic poliomyelitis begins with an infection in children at ages 5 and under (National Institute of Neurological Disorders and Stroke, 2012). Symptoms usually start with a fever and headache and then swiftly progress to muscle weakness and paralysis. For those who do not recover, permanent paralysis of skeletal muscles impinges on activities such as walking, breathing, reaching, or holding the torso straight. This becomes a way of life from an early age. From the 1950s through the 1980s up to 350,000 cases were reported each year worldwide (World Health Organization [WHO], 2013). Then immunizations were released and the disease became less common. From 2003 to 2005, 25 countries that were previously polio-free saw polio infections due to the virus being brought in by visitors from

other countries (WHO, 2013). Currently, only Afghanistan, India, Nigeria, and Pakistan continue to report new cases of polio at endemic rates (WHO, 2013).

In the United States, poliomyelitis is considered a common neurological condition despite our having an effective immunization that has eradicated new cases in most parts of the world (Trojan & Cashman, 2005). Approximately 440,000 people in the United States (National Institute of Neurological Disorders and Stroke, 2012) and over 20 million worldwide (WHO, 2013) live with the late effects of polio. Researchers studying those aging with the effects of polio contribute critical pieces to literature because of the gained knowledge about the changes that occur over time in those living with paralysis (Alexander, 1990; Harrison, 2006).

Researchers have explored the prognostic factors that indicate the potential for transformation in bodily function and subsequent life patterns over time for those aging with paralysis. These include the possibility of acquiring postpolio syndrome, higher rates of co-morbid conditions, and higher rates of difficulty in social participation. Postpolio syndrome is found in varying numbers of polio survivors, 25% to 60% of whom may develop new muscle weakness, fatigue, and pain over time in muscles previously affected by polio (National Institute of Neurological Disorders and Stroke, 2012). Many researchers have highlighted the elevated risk for co-morbid conditions that people with polio experience with age. For instance, cardiac risk factors were reportedly assessed less often but were higher for people aging with polio than in the general population (Gawne, Wells, & Wilson, 2003). Further, persons aging with polio followed for over 20 years showed higher rates of hospitalizations for pulmonary disease, heart disease, gastrointestinal disorders, and musculoskeletal disorders than did age-matched contemporaries (Nielsen, Rostgaard, Askgaard, Skinhøj & Aavy, 2004). Finally, polio survivors have reported an inability to maintain social activities as their impairments increase with age (Yelnik & Laffont, 2009). Polio survivors often struggle with maintaining societal activities associated with specific gender roles, which can influence their overall gender satisfaction. If a polio survivor is dissatisfied with his/her gendered outcomes within society, this can influence how he/she views the disability, as well as his/her self-esteem, physical performance, familial interactions, and health outcomes (Glover-Graf, 2012). Polio survivors can have difficulty with life satisfaction and depression if they have negative views of their disability and poor family function (Kemp, Adams, & Campbell, 1997).

Theoretical Framework

The work of West and Zimmerman (1987) provides a theoretical background with which to build an understanding of gender satisfaction among women with disabilities due to paralytic polio. West and Zimmerman argue that gender is the “activity of managing situated conduct in light of normative conceptions of attitudes and activities appropriate for one’s sex category” (p. 127). Gender is therefore not to be thought of as a set of characteristics, but as the performance of a role, a consequence of social events and interactions. Gender is not a biologically innate trait that we are born with, it is developed as we grow and learn society’s expectations about our sex category. Given that gender is based on social expectations and norms attached to sex, West and Zimmerman argued that one *does gender*: “Doing gender

means creating differences between girls and boys and women and men, differences that are not natural, essential or biological” (p. 137). Doing gender consists of putting on a performance, meeting society’s expectation that a person should fulfill the role of a male or female within society. Gender performance becomes an expectation as soon as we are born and placed in a blue or pink blanket (Valeras, 2009).

There is a significant amount of literature on doing gender; Wickes and Emmison (2007) identified 149 such articles and book chapters published in the social sciences from 1989 to 2005. The usefulness of this construct has also found its way into disability studies, which are grounded in qualitative research: When researchers examine gender and disability, controversial social beliefs, stereotypes, and labels are uncovered (Vilchinsky, Werner, & Findler, 2010). Doing gender was initially an ethnomethodologically informed process for understanding the product of gendered interactions. Researchers that examine doing gender focus not on what a person believes he or she *is* but on what the person *does* which can only be studied with observational methods (Wickes & Emmison, 2007). Wickes and Emmison rebuke those who appear to be unfamiliar with this process and subsequently use the concept inappropriately as a theoretical tool. According to Wickes and Emmison, doing gender cannot be studied with survey research techniques. Our Gendered Outcome Scale is a tool used to measure gender satisfaction, not doing gender. The women in the present study were asked to reflect on their interactions and to comment on their satisfaction with those gendered interactions. Although our work is influenced by the theoretical work of West and Zimmerman (1987), we do not claim to study the process directly. We believe that a woman’s self-appraisal of her gendered interactions may be more influential regarding health outcomes than observational studies of the interactions.

Methods

Sample

The participants in this study were 295 women with a reported age ranging from 49 to 83 years ($M = 65$ years, $SD = 5.8$). The reported age for contracting polio ranged from 13 to 31. At the time of the study, 17% were unemployed due to disability ($n = 49$) and 46% ($n = 134$) reported being retired; 4% ($n = 13$) reported an income of \$10,000–\$15,000/year, 8% ($n = 24$) reported \$20,000–\$25,000, and 21% ($n = 62$) reported \$50,000–\$75,000. The majority of the women reported being non-Hispanic White, twenty-five women reported African American as their ethnicity, and one woman reported Asian as her ethnicity. Further descriptive statistics for the sample are displayed in Table 1.

Data Collection

The procedures for recruitment and data collection have been reported in Harrison’s (2009) study of health promotion. A total of 500 women with a history of paralytic polio who had participated in that study and had consented to further contact were asked to participate in the present study. The potential participants were mailed an informational letter and a stamped return envelope after approval was obtained from the local institutional review board. Within 2 months of the mailing, over 60% responded. No incentives were offered for

completion of the study. However, both a hand-written thank you and preliminary descriptive results were sent to all participants upon completion.

Each participant in this study completed a battery of questionnaires, titled the Women Aging with Polio Questionnaire. This included the measurement tools and demographic questions discussed below. A total of 301 questionnaires were returned; 295 had complete data and were therefore used. Data were entered into SPSS and were checked for accuracy.

Measures

Demographic questions regarding age, ethnicity, age of polio diagnosis, type of polio, and other factors were asked at the beginning of the questionnaire.

The revised form of the Health Assessment Questionnaire (HAQ) was used to measure functional limitation in the sample (Fries, Spitz, Kraines, & Holman, 1980). The HAQ includes 20 items and can be used to measure the amount of difficulty with function across eight domains: grabbing, standing, eating, dressing, walking, hygiene, reaching, and activity. To obtain the final HAQ score, the scores of these 8 domains are added and then divided by 8. The scores range from 0 to 3, with 3 indicating poorer function. Cronbach's alpha for the HAQ in this sample was .91.

Disability was measured using the Craig Handicap Assessment and Reporting Technique (CHART; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1988). The CHART can be used to measure one's ability to fulfill social roles across various domains. This 20-item instrument has six dimensions: physical independence, mobility, occupation, social integration, economic self-sufficiency, and cognitive independence. A total score less than 450 or a subscale score less than 75 indicates disability. A higher score on the CHART indicates less disability being reported by the participant. The test-retest reliability of the CHART was not calculated for this study because the instrument was administered only once. Researchers have previously reported a test-retest coefficient of .93 for the CHART (Cusick, Gerhart, & Mellick, 2000; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992)

Scale Development

On the basis of our qualitative research (Harrison, 2006; Harrison et al., 2011) and with an eye toward the work of West and Zimmerman (1987), gender satisfaction was conceptualized and operationalized for measurement. As we have said, this concept is based on the theory of doing gender but is not a direct measurement of doing gender. According to West and Zimmerman, gender is the product of interactions with other people. It is an "emergent feature of social situations" (p. 126) where people achieve a self-appraised gendered status. Gender satisfaction is a concept reflecting a woman's appraisal of her own gender performance and subsequent satisfaction with that interaction. In operationalizing this concept, we used five items consistent with this perspective. Following recommendations of DeVellis (2012), in order to validate the applicability of these items, we consulted a panel of four experts in disability studies and feminist theory. These experts ranked the items based on level of relevance to satisfaction with gendered outcomes. All five of the items on the scale were validated through this process. Although the experts' rankings

showed a consensus that the scale measured the construct, two of their comments suggested improvements. One recommended that we include the option of “man” for studies that include men. The second recommended that we separate the items that had combined family/community in one question into two separate questions instead. See the scale items in Table 2.

The five items of the Gendered Outcome Scale consist of questions such as “As a woman, I am pleased with the way my family/community interacts with me.” Responses are given in the format of a 5-point Likert scale ranging from 1 being designated as *strongly disagree* to 5 being designated as *strongly agree*. For analysis, reverse coding was necessary on Items 2 and 5 before adding the total scores. Total scores on the scale range from 0 to 25; the higher the score, the higher the gender satisfaction.

Data Analysis

Data analysis was conducted to test the Gendered Outcome Scale’s validity and reliability. As DeVellis (2012) has explained, to have a scale with highly intercorrelated items, each individual item must be strongly correlated with the remaining items. To assess the construct validity and appropriateness of the scale’s five items, principal components analysis (PCA), Bartlett’s test of sphericity, varimax rotation and Kaiser-Meyer-Olkin were analyzed. PCA effectively measures how well the scale’s items measure the intended construct (DeVellis, 2012). Kaiser-Meyer-Olkin is a measure of sampling adequacy, and significance of the Bartlett’s test of sphericity indicates items are correlated (DeVellis, 2012). Cronbach’s alpha was calculated to determine reliability. Cronbach’s alpha indicates the amount of variance in the scale scores that is attributable to the true score (DeVellis, 2012). Pearson correlations were completed to examine relationships between variables.

Results

Data were from the 295 participants aging with the effects of polio. The correlation matrix of the items consisted of values greater than .3 and less than .9. Bartlett’s test was significant and the Kaiser-Meyer-Olkin was .93. The PCA yielded one component with an eigenvalue above 1, which explained 71% of the variance. The scree plot analysis showed a drop after the first component; therefore, all questions were loaded on the one component. In Table 2 the factor loadings from the varimax rotation of the PCA for the scale items are presented. In Table 3, the means, standard deviations, and ranges for the instruments are displayed; the measures performed as they were intended. Internal consistency reliability was based on one component of the Gendered Outcome Scale; Cronbach’s alpha was .90. Gender satisfaction was significantly related to function, $r = .181$, and inversely related age, $r = -.173$, with $p < .01$ for both. There was also a significant relationship between gender satisfaction and disability, $r = -.127$, $p < .05$.

We found that the results of this study support that the Gendered Outcome Scale is a valid and reliable tool for examining gender satisfaction. In addition, we found a significant relationship between gender satisfaction and function. As functional limitations increased, gender satisfaction increased. Gender satisfaction was also significantly related to age and disability: Younger women had more gender satisfaction, and the more disability, the greater

the gender satisfaction. As their function declined, their satisfaction with their gender increased. Aging and functional limitations may have influenced the women's gender interactions, which may in turn have influenced their overall gender satisfaction. Function, age, and disability can therefore greatly influence gender satisfaction and experiences of women aging with the effects of chronic conditions. The findings of this study were not similar to previous work such as Valeras (2009), where women with hidden disabilities were able to transform their gender role identities. The women in this study may have experienced more gender satisfaction with more functional limitations because more physical functional limitations may have been observed by society, which may have resulted in less gendered expectations. In addition, if the women had more social role performance (more disability) they may have been more engaged in social roles such as mother or employee that may have increased their gender satisfaction. Performance expectations at a place of employment or in other arenas of society may lead to specific gender expectations (Ridgeway, 2002), which may influence gender satisfaction outcomes. Although there has been no research examining the relationship between gender satisfaction and function, disability, and age in women aging with paralytic polio or any other chronic condition, researchers have reported that women feel conflicted or negative about gendered outcomes as well as their bodies because of social beliefs surrounding femininity and pressure to remain young (Winterich, 2007). The body is "a tool that communicates the junction of both gender and ability" (Valeras, 2009, p. 5). Bodily and social performance is formed by, and even limited to, the cultural beliefs, norms, and expectations of one's particular situation (Valeras, 2009). It is important to look at these relationships so that we can gain further understanding about how gender satisfaction is influenced as women age with chronic and disabling conditions.

Limitations of the Study

This study is based on self-report, and the findings are limited to women with polio living in the United States and not generalizable to persons aging with chronic and disabling conditions from other cultures or living in other areas of the world.

Discussion

The Gendered Outcome Scale should be tested further in aging populations with other diverse chronic and disabling conditions. Researchers have recommended that in order to confirm correct translation and validity of an instrument for other countries the instrument must be forward and back translated in each language that it is to be used, and the psychometric properties should be tested among moderate to large sample sizes (Bullinger, Anderson, & Aaronson, 1993). Future research is needed to examine the relationships between gender satisfaction, age, and disability in both men and women who are experiencing disability from various chronic conditions.

Researchers who focus on gender issues for diverse groups of women such as women with disabilities can provide "more nuanced theory on how gender influences illuminate further the consequences for women's daily lives, sense of selves and relationships with others" (Winterich, 2007, p. 67). If researchers can gain further understanding of the complex relationships between gender outcomes and health outcomes, this will provide knowledge

for developing interventions to improve health outcomes and health behaviors in women aging with disabilities. As society gains further understanding of how women with disabilities navigate their roles in society and how their bodies interact with the world, society as a whole can begin to provide better services, resources, and health care for women with disabilities (Harrison et al., 2011).

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Table 1

Demographic Information

N= 295				
		Mean (Standard Deviation)	Frequency	Percentage
Age		64.95 (5.81)		
Employed				35.3%
Non-Hispanic White				90%
Had Children				97%
Type of Polio				
	Spinal		151	
	Bulbar		15	
	Both		51	
	Unknown		65	
Reported having Post Polio Syndrome				78%
Marital Status				
	Never Married			12%
	Married			62%
	Divorced			11%
	Widowed			10%

Table 2

Varimax Rotation of Principal Component Analysis

Gendered Outcome Scale Items	Factor Loadings
Item 1	.90
As a woman I am pleased with the way my family interacts with me.	
Item 2	.86
I dislike the way people in my family/community respond to me as a woman.	
Item 3	.83
I am treated the way I think a woman should be treated.	
Item 4	.83
I am always treated fairly as a woman	
Item 5	.80
I think I could be treated better as a woman.	

Table 3

Psychometrics for Instruments

Variables	Measures	Mean (Standard Deviation)	Range	Cronbach α
Gender Satisfaction	Gendered Outcome Scale	11.02(4.22)	5-23	.90
Functional Limitations	Health Assessment Questionnaire	7.06 (4.96)	0-21.38	.91
Disability	Craig Handicap Assessment Tool (CHART)	437 (73.10)	167-516	N/A *

* The test-retest reliability for the CHART was not calculated because it was only administered once. Researchers have previously reported an test-retest coefficient of .93 for the CHART